"Information Work" and Chronic Illness: Interpreting Results from a Nationwide Survey of People Living with HIV/AIDS

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While there is a substantial body of research which describes how the HIV-positive community seeks and uses information, much of that work fails to consider these activities in relationship to the experience of living with long-term chronic illnesses. In this paper, we present results from our survey study on the information preferences and practices of the HIV-positive community. We compare our results to previous findings on the HIV-positive community and people living with another chronic condition, multiple sclerosis (MS). Applying the chronic illness trajectory model developed by Juliet Corbin and Anselm Strauss, we examine what this body of research tells us about the management of "information work." We identify the information sources that are most important, the attributes of information that influence its use, and the tensions inherent in managing information in the day-to-day lives of the chronically ill. By extending Corbin and Strauss's model to the aspects of information emphasized across studies, we begin to articulate the fundamental nature of information work in living with chronic illnesses and how information services can be more responsive to the needs of the chronically ill.

Introduction

HIV/AIDS as Chronic Illness

HIV/AIDS is now widely considered a chronic disease. Chronic illnesses are long-term by nature, often involve multiple ailments, are associated with a range of uncertainties, require considerable palliative efforts and ancillary services, tend to interfere with the lives of the ill and their loved ones, and are expensive to treat and manage (Strauss et al., 1984). Acute conditions differ in that they are usually isolated to one area of the body, last a finite length of time, have identifiable causes, and respond to treatment, often allowing the afflicted person to return unimpeded to their former lifestyle (Murrow & Oglesby, 1996). Currently, chronic illnesses impact the quality of life of 90 million Americans (CDC, 2005) and significantly limit the activities of more than one in every ten Americans (CDC, 2004). As Register (1987) explains, several decades ago, many of these individuals would probably have passed away before they reached middle-age. However, the effect of these conditions has been tempered by enhanced diagnostic procedures, more effective treatment for acute problems, and improved means of maintaining health. In this sense, chronic illnesses like diabetes mellitus, hypertension, and others are both "a personal misfortune and a sign of progress" (p. ix).

Although there has been considerable progress in the control of symptoms and effects for some conditions, people are rarely completely cured of chronic illnesses. They can be experienced as interruptions or intrusions on life, but for many their lives become dominated by the management of disease-related complications and responses to crises. The chronically ill often find themselves completely immersed in their illnesses (Charmaz, 1991). The experience of serious chronic illness has been described as a kind of continual "hovering" between the states of suffering and enduring, along with the ongoing process of reformulating the self (Ohman et al., 2003). Strauss (1981) argued that "multiple problems of living" go hand in hand with chronic illnesses and can reach into every part of a person's life. They include preventing and managing medical crises, managing symptoms and treatment regimens, efficiently organizing one's time, preventing or coping with social isolation, adapting to changes in the trajectory of the disease, and normalizing one's life despite illness.

When the first cases of what we now know as HIV/AIDS were reported in the United States, it was identified as an acute disease, one that often proved fatal in a matter of months. However, as Beaudin and Chambre (1996) explain, a range of medical, epidemiological, and social factors throughout the 1980s contributed to a reframing of HIV/AIDS as a chronic disease. While activists

made known the extensive needs of the HIV-positive community, biomedical research provided more insight into the HIV-virus and its effects on the body, and the kinds of services and care available to the increasing numbers of HIV-positive people slowly became more inclusive. Perhaps most importantly, the late 1980s saw the development of new treatments like the antiretroviral medication AZT. A still broader shift towards chronic models for understanding HIV/AIDS began in 1996 with the introduction of protease inhibitors (PIs) (Kopp, 2002). When taken in combination with other anti-HIV medications, PIs can lessen the dangers of opportunistic infections, control the ability of the HIV virus to copy itself in the body, and increase a person's CD4 cell counts. For the many people living with HIV/AIDS (PLWHA) who have access to and success with these treatments, life has been prolonged.

Fee and Fox's (1992) characterization of HIV/AIDS as a lengthy, slow disease process is still accurate today. Moreover, the experience of living with HIV/AIDS overlaps in fundamental ways with the experience of other long-term chronic illnesses. While there is still no cure for the disease, current treatments are more effective than ever at impeding the negative effects of the HIV-virus and extending the lives of HIV-positive people. PLWHA also have to confront emotional distress, stigma, and feelings of uncertainty, reconsider their social roles, interpersonal relationships, and identity as patients, adhere to complicated drug regimens, and engage in a range of other self-care activities (Siegel & Lekas, 2002). Their experience with the disease can also be described in terms of phases, including lengthy periods of symptom-free stability, and acute episodes requiring medical attention (Strauss, Fagerhaugh, Suczek & Wiener, 1991). Approaching the experiences of PLWHA from the perspective of chronic rather than acute illness draws attention to these dynamic, temporal, and social aspects of managing long-term illness and illuminates chronic illness as a way of life—a life in which information plays a vital role in an array of day-to-day situations.

Chronic Illness Information Work and the Trajectory Model

The concept of information work fills the space between two more established concepts in the LIS field: It is broader than information seeking but narrower than information behavior. Information seeking refers to "purposive" behavior (Wilson, 2000) and has been defined as "a conscious effort to acquire information in response to a need or gap" (Case, 2002. p. 5). Information behavior is broader in scope and refers to "the totality of human behavior in relation to sources and channels of information" (Wilson, 2000, p. 49), from the unintentional and passive to the purposive (Case, 2002). Because it includes behaviors beyond acquiring information,

information work is not as limited a concept as information seeking. Yet at the core of information work reside purposive, conscious, intended actions. As such, the concept is not as encompassing as information behavior. It puts the focus on the actual labor—the time, effort, resources, and outcomes—necessary in finding and using information, and it accounts for what is done with information after it is sought and found, whether it is assimilated, passed on to a peer, or just filed away for future reference.

All types of work involve some kind of production, construction, consumption, or use of information (Gerson as cited in Strauss, Fagerhaugh, Suczek & Wiener, 1997), and as Corbin and Straus (1988) explain, without successful information work, other kinds of work cannot be completed. Comparable to other varieties of articulation work, the seemingly mundane organizational, coordinating, and planning activities involved in getting things done, the information work of the chronically ill and those around them is a necessary component of the work of living. Chronic illness information work involves the quest for, the receiving of, and the passing of information (Corbin & Strauss, 1988), as well as networking, scouting out, coaching and training, providing and clarifying instructions, differentiating between needs and wants, and searching for people, places, and things (Corbin & Strauss, 1985b). In other words, activities that involve locating and interacting with information, activities as wide ranging as reading pill inserts that come with prescription medications, calling a physician or local pharmacist for clarification, and then sharing what was found with a weekly support group, are instances of information work.

Information has long been understood as an important resource for people dealing with and comprehending the problems associated with chronic illness. Medical sociologists have argued that information about a person's chronic illness can help them understand what is happening with their body, situate their experiences in both the medical and social worlds, lessen their fears and misunderstandings, and in turn promote a sense of personal control and decreased dependence on others (Schneider & Conrad, 1983). Conrad (1987) also included information, information sharing, and awareness among the most prominent and recurring themes in studies of the experience of illness. Accordingly, information has also been understood as a critical resource in efforts to manage the complications that accompany an HIV positive diagnosis, for prolonging the life of PLWHA, and preventing transmission of HIV (Huber, 1998). But Corbin and Strauss's concept of "information work" moves beyond the notion of information as resource to account for the actual labor of locating, gathering, sorting, interpreting, assimilating, giving, and sharing information, and the fundamental nature of these activities in living with chronic illness. To help bring together these various aspects of information work, we utilize Strauss and Corbin's (1988) chronic illness trajectory model, which we discuss further below.

Drawing on research from the sociology of occupations and work, Corbin and Strauss (1985b, 1988) argue that living with chronic illness requires the ill person and people around them to engage in significant amounts of work. When illness surfaces, people usually make some effort to manage and control it. But management cannot happen nor can control be achieved without the many tasks required to "carry out a plan of action designed to manage one or more aspects of the illness and the lives of ill people and their partners" (Corbin & Strauss, 1988, p. 9). Unlike acute illness, home is the central site or workplace for chronic illness, and most of the work is done by the ill themselves and their family, and the tasks and the nature of that work changes in different phases of the illness (Strauss & Corbin, 1988). Three major types of work are involved: (1) illness work, (2) everyday life work, and (3) the biographical work of maintaining psychological heath (Corbin & Strauss, 1985b). These and other kinds of work are represented in Strauss and Corbin's (1988) trajectory model, which emphasizes the maintenance of quality of life, changing phases of illness, the different people involved in managing illness and their roles and relationships, and the arrangements necessary to carry out work. The model provides a cogent social science perspective on the management of chronic illness that extends beyond medical institutions and the clinical context, emphasizing everyday life, where information work is a pervasive activity of great importance.

The practice of information work is clearly a central part of the experience and management of chronic illness, and HIV/AIDS is an archetype of chronic illness. Therefore, we would expect similar patterns of information work among PLWHA and others with different chronic illnesses. In this paper, we look at the congruence of our results from a nation-wide survey of PLWHA with previous studies of HIV/AIDS and extend that comparison to studies of multiple sclerosis (MS), a chronic autoimmune disease that affects the central nervous system. The HIV-positive and MS communities have already been investigated by several LIS scholars and as such, are good points at which to begin making comparisons and thinking about information work across chronic illnesses. In addition, we discuss what our findings suggest in terms of the actual "doing" of information work by the chronically ill and the provision of information services for them. As indicated above, different chronic illnesses share many common characteristics, and there can be considerable overlap between the experiences of people living with different conditions. As a point of caution however, we cannot assume a complete overlap between the experiences of people living with different chronic illnesses – illness trajectories and the influence of social forces on different disease experiences are too varied. For example, differences in the availability and effectiveness of treatment, the extent to which healthcare and social services infrastructure is developed, and varying levels of stigma and uncertainty can render the experience of one chronic illness somewhat different from another. The many factors that shape and re-shape the illness experience also affect the need for particular kinds of health-related information, the information sources that are available, and the work necessary for the chronically ill and others to interact with and use that information.

Methods

We collected data through a self-administered mail survey distributed nationwide. Collaboration was vital to the project. By partnering with HIV/AIDS educators and activists from Visionary Health Concepts (VHC), a health education company owned and operated by people with HIV and/or the hepatitis C virus (HCV), we informed our study with the valuable expertise of those working at the front lines of the disease. All the collaborators were involved in the development of research questions, methods decisions, and the mechanics of survey design. The resulting questionnaire was pre-tested with groups of PLWHA in a mid-sized Midwestern community and in New York City. The test respondents included HIV-positive men and women of various ethnic backgrounds and levels of socioeconomic status, and former intravenous drug users. Focus group sessions were held with participants after they had completed the survey to obtain direct feedback on the questions. The test respondents evaluated the questions in terms of clarity, readability, suitability of response options, and terminology, and also shared their own experiences related to the questions. This feedback was critical in assessing and revising the question categories and wording (Hughes & DuMont, 1993; Wolff, Knodel & Sittitrai, 1993).

Participants

The survey was distributed over an eight-week period through public and private clinics with large numbers of HIV-positive clientele, drug treatment centers, and other AIDS service organizations (ASOs – agencies involved in prevention efforts and the treatment and support of PLWHA) located throughout the United States. Our collaborators at Visionary Health Concepts are engaged in ongoing educational outreach activities and frequently interact with such organizations. They selected 750 organizations they were aware of, based on location and likely demographic composition of the clientele, forming a regionally balanced mix of large, medium, and small organizations serving urban, suburban, and rural areas. The major cities affected by the epidemic, including New York, San Francisco, Los Angeles, Houston, Detroit, Miami, and Chicago were covered in the sample. The overall goal was to distribute the survey widely and reach many of the diverse groups that make up the HIV-positive community.

Measures

The survey included 35 questions. The formatting included closed-ended Likert scale questions, closed-ended questions with unordered response categories, and both partially and fully open-ended questions. Participants were asked about their information needs, the information sources they use, the barriers to HIV information they encounter, the impact HIV information has on their lives, and basic demographics. The survey also included measures to estimate the general state of health of the respondents. For example, one question was a self-report of treatment success and another asked for current and past T-cell counts (higher T-cell counts are associated with a stronger, healthier immune system).

Procedures

Survey packages consisting of questionnaires, postage-paid reply envelopes, cover letters, and instructions for distributing the survey, were sent to the 750 organizations. Initially, we mailed 10 surveys to each organization and then followed up with telephone calls to monitor distribution rates. Some organizations were sent anywhere from 10 to 100 additional surveys during a second wave of mailings. Approximately 200 surveys were hand-delivered to organizations within the New York metropolitan area after our collaborators determined this to be the most efficient way to reach people at these sites. In total, 10,500 surveys were distributed. The staff members at the organizations disseminated the survey in ways that worked best for their clientele and local situation. For example, some mailed the survey to all of their clients and others handed out the survey when clients visited the clinic.

As a means of compensating everyone involved, survey respondents had the opportunity to submit their names to a lottery for a cash prize of $2,000. The winning respondent could then keep half of this amount and give the other half to the non-profit service organization of their choice. To keep the survey data anonymous, we devised a "2 envelope system" to separate participant surveys from their lottery registration information. Return envelopes included no printed indication that the survey and lottery were AIDS-related. Some organizations offered additional compensation, such as transportation passes, for those clients who agreed to complete the survey. To facilitate the data collection process, we established a toll-free telephone number that either staff members

or respondents could call if they had questions about the study or needed assistance in distributing or completing the survey.

Respondent Profile

Six hundred and sixty two (N=662) usable surveys were returned from 42 states over a five-month period. Some additional surveys were discarded either because the respondent was not HIV-positive or because they left portions of the survey blank. The base on which we calculated the following percentages fluctuates somewhat due to item non-response. The results that follow should be understood only in light of the limitations of our survey distribution procedures. First, although it is typical in survey research to calculate and report a response rate, our distribution procedures prevent us from doing so. We know that we distributed 10,500 instruments to various organizations, but it is impossible to know how many of those surveys were actually offered to possible respondents. Based on calls to various organizations, we know that many survey packages did not reach a staff member who was able to recruit participants for the study, despite the fact that we mailed over 95% of them to a specific named individual. Several organizations also later said they could not participate in the study due to time constraints and the deadline for returning completed surveys. Still other organizations requested additional surveys in quantities that later turned out to be overly optimistic given the time that their staff members had to speak with clients about the study.

Our distribution technique also prevented us from forming a randomized sample. We specifically targeted organizations that serve diverse clientele and we included instructions on how to distribute the survey, but we don't know how the surveys were actually distributed at the various sites. Health and social service professionals face hectic schedules and sometimes overwhelming demands, and we expect they did the best they could under these circumstances. Our sample is a subset of PLWHA who, upon receiving the survey, were willing and able to complete it. As such, we cannot accurately determine how well the respondents represent the larger PLWHA population. Finally, because our survey was distributed at health and service organizations, it only made it into the hands of PLWHA who utilize such organizations. Unfortunately, we can say nothing about those individuals who either have no access to or choose not to use such resources. However, our research team was willing to accept these various shortcomings for one key reason: our approach to survey distribution allowed us to distribute the survey widely and reach many of the diverse groups that make up the HIV-positive community. Table 1 shows the demographic breakdown of our sample.

All questionnaires were processed and entered into a database by experienced data entry staff. This paper is based on frequencies and first-round cross-tabulation analysis. In the following section, we present selected results from our survey and, where possible, compare them to previous findings on both the HIV-positive and MS communities.

Table 1. Demographic description of sample

Composition	Number of Respondents*
Gender:	
Men	440
Women	203
Transgendered/Other	7
Ethnicity:	
White	264
African American	228
Hispanic	126
Other	14
Native American	12
Asian/Pacific Islander	5
Age:	
18 – 29	35
30 – 39	214
40 – 49	275

Age:

18 – 29	35
30 – 39	214
40 – 49	275
50 and over	126

Sexual Orientation:

Homosexual	299
Heterosexual	289
Bisexual/Other	55

Education:

Some high school	93
High school graduate or GED	148
Some college or tech/trade school	265
Bachelors degree	101
Masters or doctoral degree	33

Intravenous Drug Use (IDU):

IDU transmission definite or likely	102

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*Demographic information was not fully reported across all surveys.

Results and Discussion

Information Source Preference

The survey explored respondents' assessments of HIV information sources along several lines. One question asked, "How do you best like to get HIV information?" and provided a series of options and space to write in "other" sources not listed. Respondents were instructed to put the numbers "1," "2," and "3" next to their top three choices. Figure 1 shows the percentage of total respondents who counted the information source as one of their top three ways to get HIV-related information. Seventy percent of respondents ranked doctors among their top three sources of information. It is worth noting that 43% of respondents listed doctors as their first choice. HIV-positive counselors and magazines had the next highest frequencies, although more than 30% lower than doctors. Brochures and newsletters followed in rankings but both had very low "first choice" frequencies. The Internet was not rated highly overall, with only 14% of respondents listing it as one of their top three information sources.

While the lowest rated information sources in Figure 1 are not widely preferred, they appear to be used more often by some segments of the HIV-positive community than others. For example, people who did not complete high school were three times more likely than college graduates to choose videos as a top-three choice. African Americans and Hispanics were half as likely as white participants to choose the Internet as an information source. There was also variation based on how long respondents had known they are HIV-positive. Doctors were still the top source by far, but for PLWHA who had lived with HIV for less than 10 years, HIV-positive counselors were ranked second. For those who had lived with HIV for more than 10 years, newsletters and forums were more commonly preferred. It may be that as people adjust to their health status and move more into the routines of managing chronic illness, they become more interested in sources that allow them to learn and "work" independently.
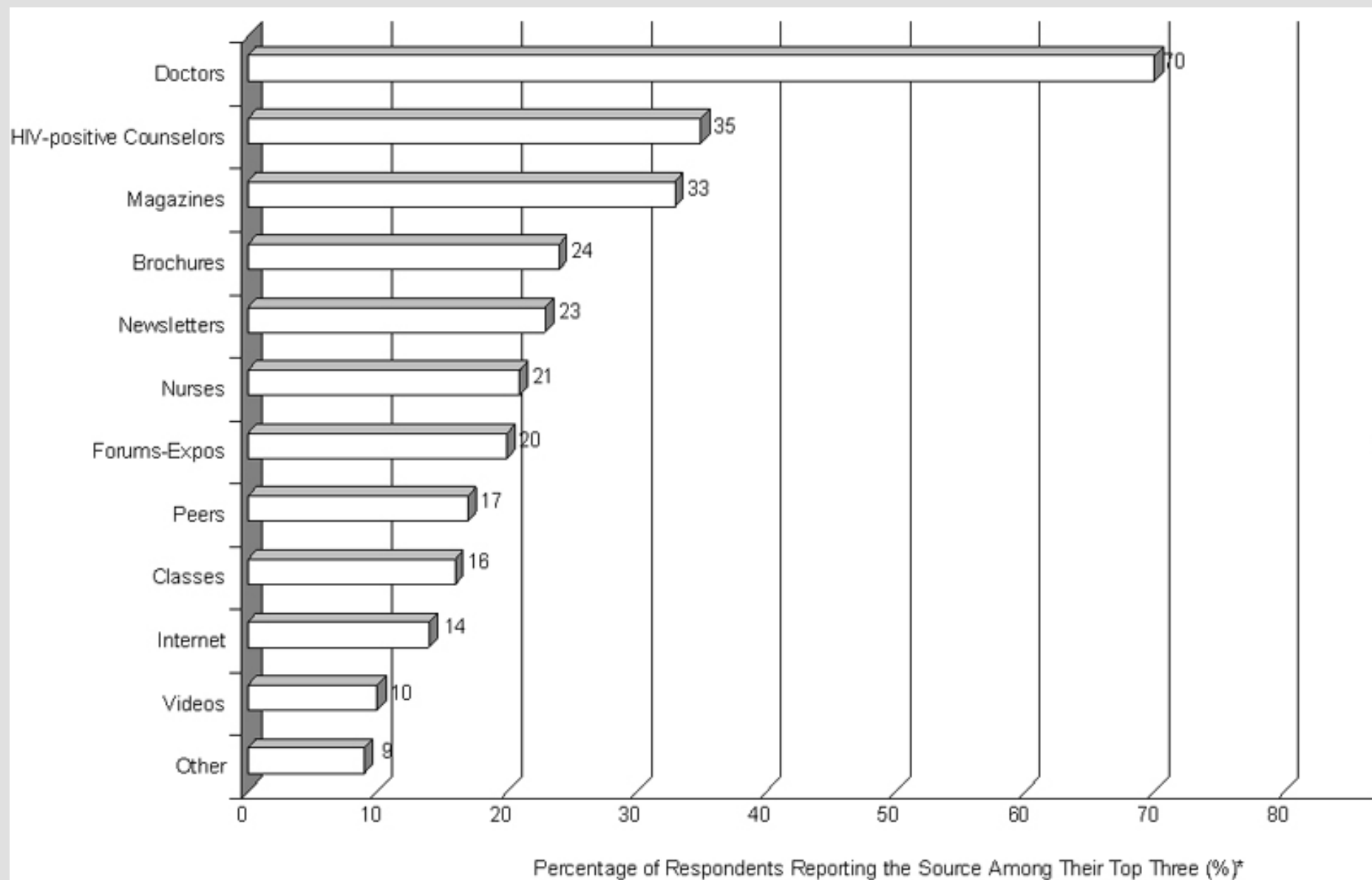
Figure 1: Sources of HIV Information *Percentages were calculated using the number of actual responses to the question. Some respondents selected less than three sources.

The clear top ranking of doctors in this study contrasts with the findings of Huber and Cruz (2000). In their study of 205 HIV-positive men and women, personal physicians were ranked slightly lower than newsletters and magazines, the two most highly ranked sources. This difference in rankings could be due to the dissimilarity of participants across the two studies, since their sample was 59% white and 90% male, of which 83% identified as homosexual. However, for people living with MS, doctors are clearly central sources of information. Hepworth, Harrison, and James (2002) found that people living with MS turn most frequently to general practitioners, and to a lesser degree other health professionals such as neurologists and nurses that specialize in MS care. Baker (1997) found that some women living with MS see their physicians as a resource not only for medical information, but also for non-medical information and were interested in discussing topics like the MS society and relevant government agencies with them. Although Baker did not find that length of time with MS was a major factor affecting the choice of physicians as a source of information, her results did show that more newly diagnosed women want to talk to their doctors than women who have lived with MS for a longer time. In a different study, Baker (1998) found that during an acute exacerbation or attack of MS, physicians, nurses, pharmacists, and physical therapists are consulted, as well as other sources. These healthcare professionals were the information providers most frequently mentioned by her participants.

PLWHA seem to use their peers for information less often than people living with MS use their peer group. In the study by Hepworth et al. (2002), other people living with MS were cited as sources of useful information as frequently as general practitioners because of their base of knowledge and ability to offer emotional support. Baker (1998) refers to both other people living with MS and support groups as traditional sources of MS-related information. In a longitudinal study, Brooks & Matson (1987) found that people living with MS sometimes realize peers are not well informed and in turn ignore their suggestions, but many consider suggestions from peers more useful than information from medical sources. However, returning to research with the HIV-positive community, "support groups" were not highly ranked in the Huber and Cruz (2000) study, and "peers" were on the low end of the preference scale in our results.

In terms of print sources, a wide range of materials is in use with no clear front runner across the different studies. In Huber and Cruz (2000), newsletters and magazines ranked very highly, slightly above personal physicians. In our study, all print sources fell quite a bit below doctors, and unlike Huber and Cruz, magazines were more highly preferred than newsletters. Brooks & Matson (1987) commented on the sophisticated reading material used by people living with MS, including publications from national societies,

government publications, and professional health magazines. Moreover, they found that this printed information is sometimes used to formulate and ask questions of doctors. Likewise, press releases, journal study results, and publications provided by national societies and health and social service professionals were used to answer questions related to exacerbations of MS (Baker, 1998). Hepworth et al. (2002) found that after face-to-face communication, leaflets, newsletters, and magazines were the information formats most preferred by their sample of people living with MS.

Based on this overview, it seems that people living with chronic illness require a mix of information from people and written sources of both a professional and lay nature. However, Strauss and Corbin's trajectory model suggests that some of the variance in source use observed across the HIV and MS studies could be attributed to the need for different sources at different phases of illness, a factor that is not accounted for in some studies. In both the HIV/AIDS and MS communities, healthcare professionals, particularly doctors, are key information sources. In the studies that reported importance rankings, they were either the most frequently cited source, or among the top three most frequently cited. As we explain below, of all the information sources represented on our survey, doctors were rated the highest in availability. However, their centrality as information sources still raises interesting questions about access and communication given that much of the work of chronic illness is done outside of formal healthcare settings, and individuals living with conditions like HIV or MS find themselves as patients in clinical contexts only some of the time. Should healthcare professionals make more of an effort to disseminate and share information beyond hospital walls? What implications does this have for the use of communications technology (e.g. email exchanges between the chronically ill and their physicians) and the development and promotion of telemedicine?

Information Work Indicators

Several questions throughout our survey asked respondents to reflect on their level of information activity. Table 2 shows a fairly high level of information work activity with a large majority agreeing or strongly agreeing that they actively search for information and regularly read to learn more about HIV. Moreover, information sharing is a common practice. Eighty percent of respondents agreed or strongly agreed that they give advice or tell others where to get information. Although they did not directly measure levels of information activity, Brooks and Matson (1987) observed that people in the MS community strive to know "the how of illness

management and are selective and experimental, even playful, with the information they garner" (p. 85).

Table 2. Information Work Indicators

Survey Questions	Strongly Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree
I actively search for new HIV information.	6%	7%	15%	24%	48%
I regularly read things that help me learn more about HIV.	3%	4%	11%	31%	51%
I try to give friends advice about HIV or tell them where to go to get more HIV information.	6%	4%	10%	24%	56%

Note: Percentages were calculated using the number of actual responses to the question.

Our results also indicate that there are some areas of illness management that could benefit from additional information work and resource development. For example, in terms of treatment options, an area we might expect to be well covered by standard information sources, 38% of our respondents agreed or strongly agreed that they don't know enough to make good treatment choices. Huber and Cruz's (2000) HIV/AIDS study also indicated that treatment was a priority. Fifty-five percent of their respondents said that they seek drug or medication information, and 44% seek treatment information. Similarly, Baker (1998; 1996) found a need for more education about the drugs used in the treatment of MS, including information about dosages, adverse/side effects, long-term effects, and new drugs. In the Hepworth et al. (2002) study, over 50% of all the respondents felt that information on drug

treatments was very important to have, and over 60% indicated that at the time they were diagnosed with MS, they wanted information on possible drug treatments. However, over 44% of all the respondents also said that information about drug treatments is either difficult or very difficult to find.

Attributes of Information

Two questions on our survey provided insights into the quality of different information sources and the effort involved in using various information sources. In one question we asked respondents to characterize how useful, understandable, trustworthy, and available 11 different HIV information sources are to them, using a 5-point Likert scale ranging from "a little" to "a lot." Table 3 presents the percentage of respondents who gave a source the highest possible rating, listed in rough descending order in terms of overall judgments. People, including health professionals and individuals from the respondents' personal lives, were rated more positively than print information and other media. Doctors, peer educators, nurses, and case managers were considered the most useful and understandable sources, as well as the most trustworthy. Friends and peers were ranked next overall, but were not particularly strong in terms of usefulness or trustworthiness. Among the print sources in Table 3, community-produced brochures were rated as the most understandable, but only a little more useful than drug company brochures, magazine articles, the Internet, or newsletters. In the second, more general question on information barriers, the most frequently selected top-three barrier to using HIV-related information was that it is "hard to understand" at 40% percent. Huber and Cruz (2000) had a comparable response to a question related to understanding of material. Thirty-two percent of their sample found HIV/AIDS information too technical to understand.

Table 3. Information Source Attributes

Information Sources	How Useful is the Source?	How Understandable is the Source?	How Trustworthy is the Source?	How Available is the Source?
Doctors	51%	48%	55%	53%
HIV-positive Peer Educators	35%	39%	36%	34%
Nurses	31%	35%	32%	36%
Case Managers	33%	37%	33%	36%
Friends and Peers	21%	31%	22%	35%
Newsletters	18%	22%	16%	25%
Community-produced Brochures	19%	30%	20%	29%
Magazine Articles	15%	21%	12%	31%
The Internet	15%	20%	12%	36%
Drug Company-produced Brochures	15%	18%	16%	31%
Advertisements	9%	18%	8%	29%

Note: Percentages were calculated using the number of actual responses to the question.

The most frequently selected first choice in the general barriers question related to applicability, with 15% of respondents listing "not enough information applies to me" as the biggest barrier. Thirty percent of our respondents listed applicability among their top three barriers to information use. Huber and Cruz's (2000) findings were similar, with 75% of their respondents stating that the information they found applied to them, leaving 25% with a presumed applicability problem. Limited applicability of information was also identified as a significant problem in the MS community. Baker's (1998) respondents who had recently experienced an acute exacerbation of MS lacked current, personally relevant information and did not consider generic MS information helpful. She goes on to argue that not having access to honest, realistic, individually tailored information can deprive a person of their sense of control and force them to depend on their doctors. In an earlier study, Baker (1996) found that many information requests made by women with MS reflect needs that are so specific, they require one-on-one interaction rather than printed material.

While there is considerable variation among sources in Table 3 in terms of how useful, understandable, and trustworthy they are to the PLWHA in our sample, there is much less difference in their availability. Doctors were rated the highest in availability with all other sources rated lower, but close together in range. Additionally, in terms of barriers, information being "hard to find" was rated as the least significant of all barriers, and 35% of respondents included "too much" information as one of their top three barriers. Clearly, useful and trustworthy information can make significant contributions to illness management, and understandable and applicable information require less effort to interpret and utilize. However, as is further discussed below, overabundant material can increase the burdens of information work.

Information Work Tensions

The high level of information work represented in Table 2 suggests that the activities are a valuable component of the many layers of work required for managing HIV/AIDS. Moreover, as shown in Table 4, a majority of respondents also indicated that they believe learning about HIV helps keep them healthy. Huber and Cruz (2000) also found that information was associated with positive emotions and a healthy outlook on life, with 84% indicating they were more hopeful about their future because of interacting with information. Similarly, the people living with MS in the study by Brooks and Matson (1987) gained confidence in choosing illness management methods and evaluating ideas by comparing information they gathered from different sources.

At the same time, information can also cause management problems and may not always be considered a positive resource. Seventy-one percent of respondents agreed or strongly agreed that it is "easy to feel overwhelmed by AIDS/HIV information." Interestingly, while a large majority of respondents are overwhelmed, a substantial segment (43%) strongly disagreed that at times it is better not to seek information. On the other hand, 31% either agreed or strongly agreed that not seeking information can be beneficial. The phenomena of information overload and avoidance have been well-documented by health and social service professionals as well as researchers. For example, mental health professionals throughout the first decade of the epidemic saw that many PLWHA felt compelled to sort through potentially overwhelming amounts of HIV information to keep up with and stay current on issues important to their health, while others tended to avoid reading or hearing about HIV/AIDS (Silven & Caldarola, 1989). Distressing information about the course of HIV infection trapped many PLWHA "between their desire to know as much as possible about HIV and their fear

of becoming immobilized by bad news" (p. 18). Brashers et al. (2000) analyzed the information avoidance strategies used by PLWHA when managing uncertainty in their lives. While information seeking can be employed to reduce or increase uncertainty, avoiding information can help PLWHA maintain a desired level of uncertainty about aspects of their condition.

These different orientations towards health information are also apparent in the MS community. Hepworth et al. (2002) found that people living with MS do not necessarily want all the information that is relevant to their health. Over half of all the respondents in their study indicated that after diagnosis they did not want information pertaining to seemingly important topics like occupational therapy, physiotherapy, possible psychological symptoms, and counseling. In at least two of her MS studies, Baker (1996; 1997) finds support for Suzanne Miller's psychological theory of monitoring and blunting which asserts that personality types account for differences in information seeking behaviors. People who "monitor" seek information to help them cope with stressful situations, but "blunters" turn away from or avoid information when they are confronted with stress (Baker & Pettigrew, 1999). However, as the trajectory model suggests, it seems likely that people shift in and out of these orientations depending on the phase of illness, the amount and kind of information available, and the management task or work at hand.

Table 4. Information Work Tensions

Survey Questions	Strongly Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree
Learning new HIV information helps to keep me healthy.	5%	2%	13%	25%	55%
It's easy to feel overwhelmed by AIDS/HIV information.	10%	8%	11%	36%	35%
At times it's better not to seek more AIDS/HIV information.	43%	11%	15%	16%	15%

Note: Percentages were calculated using the number of actual responses to the question.

Conclusion

Chronic illness does not play out only in healthcare institutions or under the watchful eye of doctors, nurses, and other healthcare professionals. It is experienced and managed in people's homes, at their jobs, and in conjunction with others. Corbin and Strauss developed their ideas about illness and the work it entails at a time when the pervasiveness of chronic conditions and its implications for the healthcare system were only beginning to be appreciated. Since then, cultural, scientific, technological, and medical forces have re-shaped the experience of many chronic illnesses, but they have not significantly lessened the workload that accompanies them. As Corbin and Strauss (1988) explain, using work as a lens makes it possible to distinguish between the various tasks that go into managing illness and to consider the context of the everyday lives of people doing that work. The trajectory model ties the work to the course and phases of illness, and highlights the roles, actions, and experiences of people, all of which impact the management of illness and hence, quality of life. Information work, then, emerges from this framework as something essential, dynamic, ongoing, and social that intermixes with, complements, supports, and is supported by other kinds of work. Information professionals who serve

the chronically ill should try to understand their clients' information activities — from collecting pamphlets at a community health center to searching the Medline database — as part of this significantly larger "program" of managing illness and maintaining quality of life. Moreover, each interaction with a client has the potential to be new and quite different, depending on changes with their disease or life situation, developments in their knowledge, and the various people who participate in their care.

The description of information work offered by Corbin and Strauss (1985b; 1988) captures many critical, information-based tasks. Yet, our survey data along with the comparisons we made to some of the existing chronic illness literature suggests there are additional tasks that should be accounted for in chronic illness information work. The many PLWHA in our study who expressed little difficulty finding HIV/AIDS information, those who felt that too much information is available, and the variety of information sources (from people to print) used in both the HIV-positive and MS communities suggests that sifting, integrating, and assimilating information are pressing management concerns. In addition, effectively utilizing some of these sources, particularly doctors and other health professionals, presupposes certain qualifications and prerequisite skills on the part of the person doing the information work, including the ability to form questions, prioritize and articulate them, listen, and comprehend. Regarding sources of questionable quality, how and when are the tasks of evaluating and assessing content accomplished? Finding applicable or personally relevant information, a problem among both PLWHA and people living with MS, obviously requires that such information be accessible in the first place. However, it also speaks to the complicated relationships between different lines of work and the consequences they hold for one another. In particular, consider information work and biographical work. Having an understanding of one's self and one's own situation can facilitate the searching for and gathering of personally relevant or applicable information. Yet it may be difficult to accomplish that kind of self-understanding given the ongoing uncertainty and likely personal and social changes that accompany life with chronic disease. Information work could quickly become formidable and daunting in such situations. Lastly, the findings from our survey as well as the existing literature indicate that our understanding of information work must encompass tasks that may intuitively seem counterproductive, particularly the blunting, turning away from, or avoidance of information. Effective information avoidance is not something always easily accomplished. It can require significant planning, organizing, and managing of communications with others, even the complete removal of one's self from environments in which undesired information is present. Indeed, one can imagine various situations in which avoiding information is more challenging, more demanding, more work for the chronically ill than gathering information.

Chronic illness information work is hard work. It requires time and energy, and can be mentally and emotionally demanding. In this

paper we have seen overlap as well as some divergence in the chronic illness information work of two communities. Future studies should continue and extend this kind of comparative analysis in an effort to uncover the similarities and differences in information work across more chronic conditions. In addition to the LIS literature, this will require the integration of findings from medicine, nursing, medical sociology, health communication, and other fields. We have offered only a brief introduction to Corbin and Strauss's theoretical framework in relation to our own research. In a different qualitative study of PLWHA, we are examining the tasks and experiences of people managing chronic illness with a particular focus on the information work associated with taking medications and following a treatment plan, what Corbin and Strauss (1985) elsewhere call "regimen work."

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Notes

[1]Poster # 26, US Conference on AIDS, Sept. 19-12, 2003, New Orleans, LA.Back

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